

Autism Diet Needs A Second Look

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The idea of a gluten free diet for those with autism was first recommended in the 1920s. The 1980s brought the idea that peptides appearing as opioids were the result of gluten in the urine of children with autism (Hurwitz, 2013). These preliminary theories produced the need for further studies to prove whether a gluten-free casein-free (GFCF) diet should be recommended for children with autism. I believe that studies are necessary for doctors to recommend such a difficult undertaking for parents, but the pendulum has swung the opposite direction and parents are not being told about the possibility of relief in symptoms through diet because nearly every study done in the last 40 years was inconclusive to support a GFCF diet (Hurwitz, 2013). Many parents are finding out about the GFCF diet through parent forums, support groups, or social media. Not only do more thorough legitimate studies need to be undertaken but parents should be, at the very least, given the choice to try the diet. This is vital to the education of students with autism because many of the autism symptoms prevent children from remaining in the general education classroom, such as anger outbursts, depression, and lower academic achievement.

Studies concerning the efficacy of GFCF in children with autism were limited the amount of participants, generally ranging from 10-20 on average. Most studies lost a percentage of participants due to children not wanting to eat the food given or parents saying following through with the diet was too difficult (Winburn et al., 2013). The children who left the study could possibly be the exact children who needed the diet the most. The results then become mediocre because the children who remain in the diet are already those who are more compliant.

Another issue that was neglected by the studies was that many children with autism have autoimmune diseases such as Celiacs and gut issues such as irritable bowel syndrome (IBS)

(Hyman et al., 2015, Whiteley et al., 2012). Children with these physical ailments were excluded from most studies. There is now a desire by those in research communities to purposely study this subset of children who have autism and gut issues. Including these children in studies could dramatically change recommendations. In the past, only one study was conducted in this manner and is looked to for reason why to attempt this kind of study again (Knivsberg, Reichelt, Høien & Nodland, 2002).

The last failure of previous studies was the lack of support and oversight of food being given to the participants. Only one study provided food to the participants, included home visits with a nutritionist and nurse (Johnson, Handen, Zimmer, Sacco & Turner, 2011). The omission of providing food to participants who are new to a GFCF diet lessens the validity to the study.

The National Institute of Health recommends that further reliable studies be done with subgroups, double-blind testing, and larger participant groups. Those who see issues with the previously completed studies are not convinced that relief from autism symptoms cannot be attained through a GFCF diet.

I completed an informal survey of parents who have a child with autism. (R.M Parker, *Alternative Autism Treatments*, 2018). Thirty-two parents responded to the survey. Forty-six percent of the parents reported that they use a GFCF diet or alternative treatment (sugar, soy, dye free) with their child, however, only one-third of the parents who use alternative treatments were suggested to do so by a medical professional. 71% percent found alternative treatments by means of their own research or a close friend or family member. While this is an informal survey, there is something to be said that 75% of parents have reported positive changes by using a diet or

alternative treatment. Parents listed that symptoms such as anxiety, tics, fidgeting, depression and academic difficulty had decreased. Over half of the parents stated that the difficulty of the GFCF diet did play a role in whether they attempted to implement it. Lastly, and most telling, parents answered a question whether they wished they had more support from their healthcare providers, 81% stated they wished they did.

I would be remiss not to add my own experience from a first-hand parent perspective. After my son was diagnosed with high functioning autism (HFA) the prescribing doctor insisted that before she prescribes antidepressants that I needed to remove gluten, dairy and red food dye from his diet. This was an incredibly difficult undertaking because my own son's diet consisted of large amounts of carbs and dairy. This type of eating behavior is common in children with autism. They crave carbs and dairy. From day 1-3 of providing a GFCF diet, my son's behavior and depression worsened with hitting, spitting, flapping, immense anger, and crying. Day four brought relief. The cloud of anger lifted and he was no longer depressed. Almost as if he had detoxed during the first 3 days.

After the success of the recommended diet, I still attempted to keep a few items in the house that my husband could eat which contained dairy. My son was tempted and snuck a few pieces; the anger returned and took many hours and sleep to overcome. This personal experience not only gives me compassion for the parents in the studies completed but also gives me a greater insight into how important it is to provide food for the study and help from a nutritionist. The whining and complaining that is accompanied by not being able to have their favorite foods

of pizza, mac and cheese and nuggets is enough for many participants to leave the study, and they did.

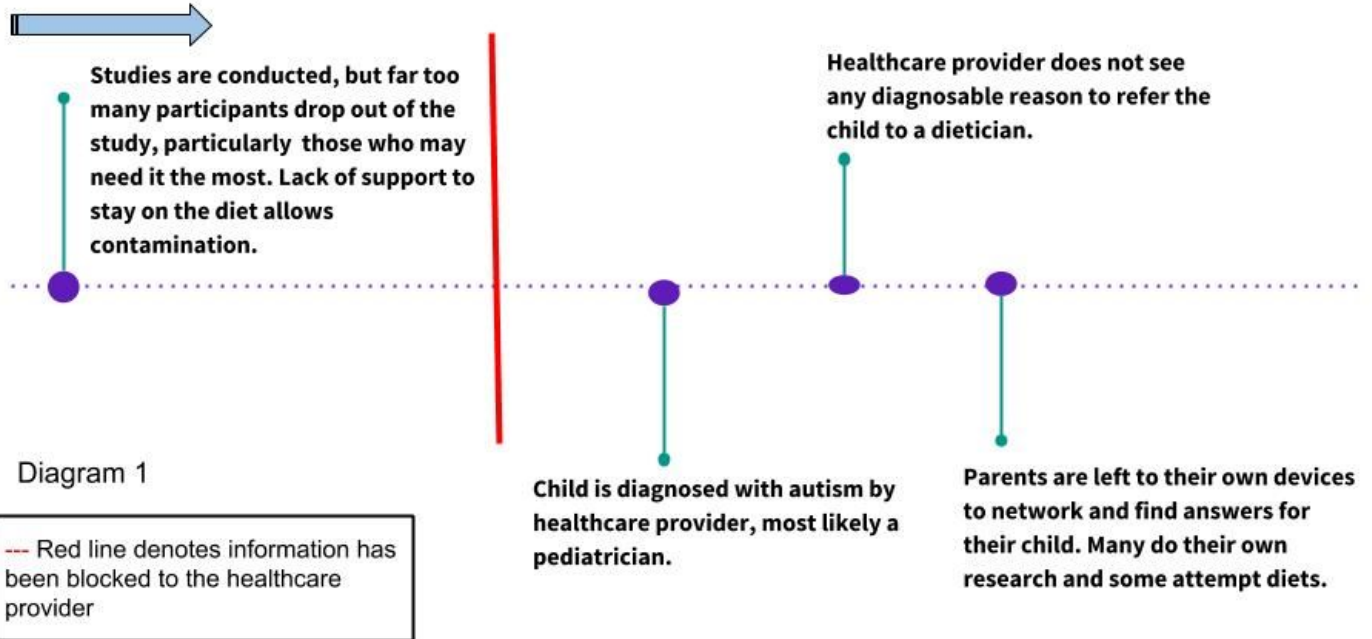
Other studies in regards to dietary needs of children with autism have been easily proved, such as vitamin D deficiency. Over 75% of children with autism have a vitamin D deficiency (Kocovska et al. 2014). This was easily proved by controlled studies through blood draws. Children with autism have complicated genetic makeup, it should not be surprising that not only are there deficiencies in their diet but also that they may require a special diet. The most recent study to date, published in 2018, conducted extensive research to prove that not only was gluten a problem but also low LDL levels in children with autism (Lee et al., 2018). Promising results were published. Significant changes in autism symptoms were recorded and scientifically measured. Parents were provided with a two hour instructional time with a nutritionist and were provided with electronic assistance from the research group anytime they needed help. This recent study is the beginning of a new wave to prove that a specific diet is crucial to children with autism.

Diagram 1 indicates what has and continues to happen when a child is diagnosed with autism. Diagram 2 shows what can be an alternative process after a child is diagnosed with autism. Primary care physicians do not have time to research every ailment and possible alternative treatments but rely on published research that is recommended by the American Academy of Pediatrics, such as, “There is little evidence to support the use of nutritional supplements or dietary therapies for children with ASD” (Sathe, Andrews, McPheeters, &

Warren, 2017). Doctors have no reason to suggest a dietary option to parents with such statements put out by their recognized organization.

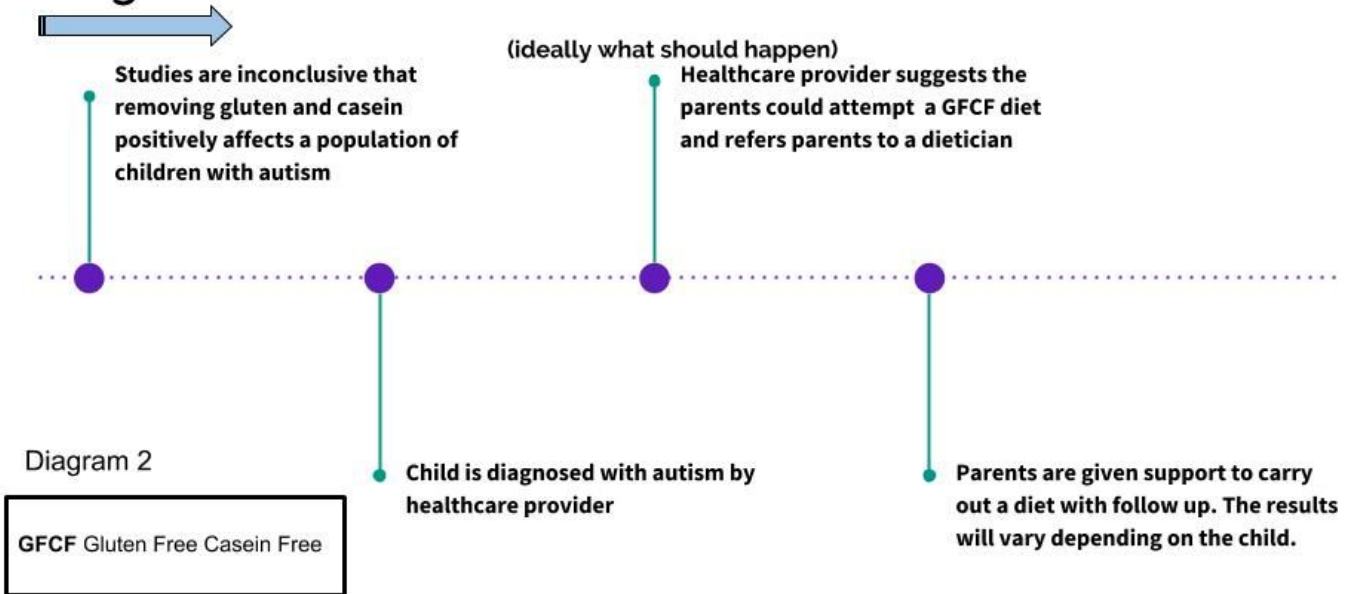
In summary, it is essential to give parents a choice. Many parents of children with autism are hearing the diagnosis for the first time and want answers and treatment options. Why not allow them to research it themselves until better studies are completed that can conclusively recommend or truly devalue the diet? I was fortunate to have my son diagnosed in a clinical setting specifically for children with autism and mental health issues. The prescribing doctor that told us to put our son on a GFCF diet may have only recommended doing so for parents based on consistent anecdotal evidence, but the 32 parents that completed my survey also agree. The GFCF diet for children with autism needs a second look and a second chance to prove itself worthy in order to reduce symptoms of those who need relief the most. Special educators could potentially spend less time on behavior management if even one-half of their caseload of children with autism responded to a GFCF diet. Children with autism should be treated holistically with their genetic makeup. Offering only behavior management and coping skills is not enough. Parents should be offered the choice to try a GFCF diet starting all the way from researchers to the child's family care doctor until the diet can be proven unnecessary or more results produced similar to Lee et al., (2018) will aid children with autism and their symptoms will be treated leading to a healthier child and improved academics.

Why children with autism are not being treated with diets



An alternative process:

Process of children with autism being referred for dietary change



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